

Dear Friends of the Foundation,

2006 ANNUAL APPEAL

It is hard to believe it is 2006! The foundation has been going strong for five years. We could not have done this without your support. We kicked off our 2006 Annual Appeal shortly before the holidays and it is off to a great start. To date we have received: \$2023.50. Thank you to everyone who has donated to the Annual Appeal for 2006.



Zachary and Benjamin

We hope to make this the biggest and best year ever for the One Small Voice Foundation. If each of our supporters made a \$100 donation to the foundation, we would raise over \$100,000. This combined with our scheduled events would bring our fundraising efforts to an all time high, but we can only reach this goal with your help. Please use the enclosed envelope to make your annual donation or go to our website www.onesmallvoicefoundation.org and click on the "Donate now" button. Thank you in advance for your continued support. Our voice is being heard as a result of your support; we are "One Small Voice" hoping to make a big impact on the research being conducted for Hydrocephalus and Optic Nerve Hydrocephalus. (Please remember we are a 501(c)3 organization and if your company offers matching gifts we should be eligible.)

This newsletter is an exciting one. It contains four excellent updates from the three research groups and Zachary's Mom. It also contains information about our upcoming events, definitions of the diseases, a photo gallery from 2005 events, the winner of the 2005 Zach Award, other ways to donate, a special thank you to our supporters and corporate sponsors and information about the second *Zak and Lizzie* book to be released in 2006.

We hope you enjoy the newsletter, we look forward to seeing you at events this year and we thank you for your ongoing support.

Peace and blessings,

Debbie, Kevin, Zachary and Benjamin Katzbeck and
The One Small Voice Foundation Board of Directors

DISBURSEMENT REPORT

The foundation closed its fifth fiscal year (August 2005) and is approximately half way through the 2006 fiscal year, we are pleased to announce that since its inception, (August 2000) the foundation has donated \$153,597.51 to research/education. The primary recipients were the Hydrocephalus Association, Childrens Hospital Los Angeles and Children's Memorial Hospital Chicago for the very important research of Hydrocephalus and Optic Nerve Hypoplasia.

As a result of your generous donations, the fact that no one in the foundation accepts a salary and the generosity of our corporate sponsors—The Orion Group and its business partners ZGraphics, Genesis and Vision Mailing—nearly 100% of your donation goes to research.

The donations were distributed as follows:

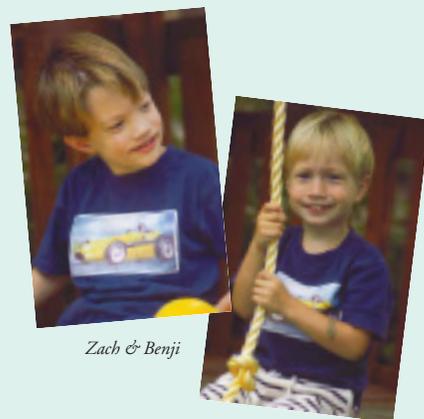
- Children's Hospital Los Angeles: \$103,800 plus a Dell Laptop Computer (\$1897.51)
- Children's Memorial Chicago: \$31,000
- Hydrocephalus Association: \$13,100
- The Guild for the Blind: \$3,500

Thank you all for your continued support. If it were not for your generosity we would not have met this incredible milestone.

WHAT IS HYDROCEPHALUS?

Hydrocephalus comes from the Greek: "hydro" means water, "cephalus" means head. Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain. CSF is produced in the ventricles, circulates through the ventricular system and is absorbed into the bloodstream. CSF is in constant circulation and has many important functions. It surrounds the brain and spinal cord and acts as a protective cushion against injury. CSF contains nutrients and proteins necessary for the nourishment and normal function of the brain. It also carries waste products away from surrounding tissues. Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.

Hydrocephalus that is congenital (present at birth) is thought to be caused by a complex interaction of environmental and perhaps genetic factors. Aqueductal stenosis and spina bifida are two examples. Acquired hydrocephalus may result from intraventricular hemorrhage, meningitis, head trauma, tumors and cysts. Hydrocephalus is believed to occur in about 2 out of 1,000 births. The incidences of adult-onset hydrocephalus and acquired hydrocephalus are not known.



Zach & Benji

HOW IS HYDROCEPHALUS TREATED?

There is no known way to prevent or cure hydrocephalus. The most effective treatment is surgical insertion of a shunt (most drain from the brain into the stomach or heart). Endoscopic third ventriculostomy (ETV) is growing in popularity as an alternative treatment method for hydrocephalus. Unfortunately, this cannot be used for all patients.

This definition was taken from the Hydrocephalus Association website. (www.hydroassoc.org). If you have hydrocephalus or are a parent please go to the website and register in the research database.

Continued on inside...

Updates from the Desk of...

DEBBIE KATZBECK

Founder/President/Zachery's Mom
One Small Voice Foundation

An Update on Zachery's Progress



In our last newsletter we updated you on Zachary's condition and, as most of you remember Fall of 2003 into Winter 2004 was a very rough time for Zachary medically. He had 10 shunt malfunctions and revisions, was battling frequent seizures and both of these—combined with his inability to produce ACTH the hormone that signals the body to make stress (cortisol) hormone—left Zachary in several dangerous medical situations. Since this last update, Zachary's shunt has been working very well (Thank you God!). Although he is still having long and severe seizures, they are further and further apart. We actually went five months without

one seizure—Hooray! The absence of the ACTH hormone has presented the majority of our challenges, but Zachary has toughed out the shots and the visits to the hospitals like a champion. The absence of the ACTH doesn't allow Zach's body to create cortisol the way you and I create cortisol. If we do not know that he is not feeling well, we can't give him steroids to replace the ACTH and thus force him to create cortisol. This is where his current challenges lie; we have found him unconscious and had to rush him to the hospital for help.

Outside of medical complications, Zachary turned 6 years old in January and is currently enrolled in a special Kindergarten program with an amazing teacher, principal and staff. He continues additional therapy at Easter Seals for Speech/Music, Physical and Occupational Therapy, as well as Miss Roberta at home for more Speech Therapy. He is a great big brother and still loves his music...and did I mention has a stubborn streak? I wonder if that comes from Mom or Dad. ❤️

TADANORI TOMITA, MD

Neurosurgery Department Head
Children's Memorial Chicago

Regarding: Neurosurgery

The Children's Memorial's Division of Neurosurgery is deeply committed to providing comprehensive care for children with hydrocephalus and we value the partnership and inspiration that the One Small Voice Foundation offers through its dedication and enthusiasm.

Over the past year, with generous support from the Willie Fund and the One Small Voice Foundation, our team has initiated a study to examine the psycho-social impact of hydrocephalus on children and their families, with a goal of addressing the special needs and quality of life issues facing children at various stages of their lives.

As you know, the intellectual, social, cognitive and emotional impact of hydrocephalus can be considerable from a patient's point of view. Yet there have been no studies to date that assess the health-related quality of life (HRQL) of these patients. Such a study will then allow hospitals and healthcare workers to cooperatively enhance the HRQL of patients with hydrocephalus and their families. Ultimately, data from this study will provide sound scientific evidence to help us advocate more effectively for further research that will lead to more successful treatments.

The Children's Memorial's Division of Neurosurgery is deeply committed to providing comprehensive care for children with hydrocephalus and we value the partnership and inspiration that the One Small Voice Foundation offers through its dedication and enthusiasm.

Since Children's Memorial treats a large number of hydrocephalic patients, perhaps the largest number in the nation, this research is extremely important to improve the quality of life of children with hydrocephalus. Each year, we care for more than 1,500 children on an inpatient basis and record as many as 5,000 outpatient visits related to the ongoing management of hydrocephalus. In addition, the division annually performs between 500 and 600 hydrocephalus-related surgical procedures, including shunt placements and revisions. Over time, the results of this research could have tremendous significance for our clinical activities, allowing us to modify treatments and improve overall outcomes for patients with all forms of hydrocephalus.

The Division of Neurosurgery at Children's Memorial Hospital is proud to partner with the One Small Voice Foundation to improve treatment options and quality of life for children with hydrocephalus and we look forward to sharing the progress of this study with you. ❤️

CASSANDRA FINK, MPH

Research Coordinator
Children's Hospital Los Angeles

Regarding: Optic Nerve Hypoplasia Research



Pamela Garcia-Filion, MPH; Mark Borchert, MD
and Cassandra Fink, MPH

The Optic Nerve Hypoplasia (ONH) research study at Children's Hospital Los Angeles (CHLA) has grown and developed in recent years. After much preparation, two new studies were approved and

opened for enrollment within weeks of one another. In order to support this growth, we have expanded our research team from a two-man show to a team of three. In May, Cassandra Fink, MPH joined the team of Mark Borchert, MD and Pamela Garcia-Filion, MPH as the new Research Coordinator. Pamela has since become a Research Associate with the study and has begun analyzing data from the first 12 years of research.

Maternal prenatal questionnaires are among the first items on the list to be analyzed. One of the most common questions parents ask us is "What causes ONH?" Well, we are actively trying to answer that question and pinpoint the risk factors associated with ONH. One way we are doing this is by conducting a standard questionnaire with each of the mothers involved in our study at CHLA. This questionnaire asks about things that took place before and during pregnancy, like place of residence and eating habits. These questionnaires, unfortunately, only reach the families that are able to participate in our research at CHLA.

In order to obtain information from families all over the country, we have developed a national on-line survey. Our survey was posted on-line in February and we have seen an overwhelming amount of interest from families across the nation. This survey is completely confidential and no identifying information needs to be given in order to complete the survey. Once we reach our goal of 1500 completed surveys, we will look for any geographic or temporal patterns and conduct further in-depth questionnaires based on the findings from the surveys. Parents can find this survey on the following websites: www.onesmallvoicefoundation.org; www.focusfamilies.org; and www.magicfoundation.org.

Additionally, our study on early treatment of Growth Hormone (GH) deficiency in children with ONH was approved and seven subjects have been enrolled since January. We are very excited about this study and all our new developments and we are hopeful that the data from our studies will prove helpful in treating children with ONH and determining their future outcomes. We realize none of our research would be possible without the commitment and support of the families involved and we are grateful to them for allowing us to observe their children and for letting us into their lives. ❤️

DORY KRANZ

Executive Director

Hydrocephalus Association, San Francisco, California

Regarding: Hydrocephalus Research

One Small Voice Foundation has encouraged and supported the Hydrocephalus Association to promote research into hydrocephalus. In the article that follows, I share with you three exciting ways in which the Association is supporting and advocating for better research into hydrocephalus.

We continue to learn from the Hydrocephalus Association Database Project, now in its third year. The goal of this project is to create a national registry to collect, store and synthesize information on the diagnosis, treatment, incidence and lifelong impact of hydrocephalus. The third phase of analysis was recently completed by Dr. Yvonne Wu, MD, MPH and her colleagues Nalin Gupta, MD and Margaret Wrensch, PhD at the Department of Neurology and Neurosurgery at the University of California, San Francisco (UCSF). Data from this set of 1,953 patients will be presented at the Annual Meeting of the American Association of Neurological Surgeons in San Francisco April 22-27, 2006. Slides from the previous year's analysis, which was presented at the Pediatric Section Meeting of the AANS/CNS on December 10, 2004, are available on the Hydrocephalus Association website at www.hydroassoc.org.

Highlights from that presentation include:

- Nearly half the survey respondents have given written consent to be contacted for follow-up information or to be notified of a scientific study for which they might qualify as a participant.
- Adult lifestyle outcomes such as working, having a driver's license and being married are correlated with older age at diagnosis and fewer shunt revisions.
- Issues of chronic headache (51%), having been treated for depression (43%) and substance abuse (9%) did not differ by age at diagnosis.

We are grateful to One Small Voice Foundation, Integra Foundation and Medtronic Foundation who made this database project possible and whose continued support will help us revise our questions and refine our analysis. We would like to acknowledge Cynthia Solomon, a founding member of the Hydrocephalus Association, for her vision and leadership on this project.

We had the pleasure and privilege of spearheading and helping to plan the first-ever National Institutes of Health (NIH)-sponsored workshop on hydrocephalus which took place in Bethesda, MD September 29-30, 2005. Over 150 neurosurgeons, neurologists, neuroscientists, patient advocates and NIH program staff joined together to dispel old myths, share new facts and decide on the most promising new directions for research. The moderators and presenters are now working together to write a manuscript sharing highlights of the presentations and outlining research priorities for hydrocephalus in the next five to ten years.

The Association also recently contracted with biostatisticians to compare the public health burden of hospitalizations for hydrocephalus between 1994 and 2004 with that of other conditions that are more well-known such as brain tumor, traumatic brain injury and childhood diabetes. We hope this information will be helpful in attracting media attention to hydrocephalus and in persuading congress to support more federal investment in hydrocephalus research through the National Institutes of Health (NIH), the Association for Healthcare Research and Quality (AHRQ) and the Centers for Disease Control (CDC).

I hope you join with us in commending One Small Voice Foundation for supporting the Association so that we can carry out this important work. 🍀

OPTIC NERVE HYPOPLASIA

Attention All Optic Nerve Hypoplasia Families!

Please be part of our groundbreaking research. Go to the One Small Voice Foundation website to connect to the research survey being done by Childrens Hospital Los Angeles. www.onesmallvoicefoundation.org. This survey can be completed on-line. Thank you for taking the time to be part of this very important research.

2005 ZACH AWARD

1st Recipient Marty Scaminaci



Kevin Katzbeck, Marty Scaminaci, Debbie Katzbeck

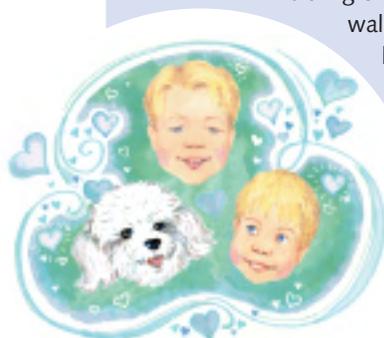
In June 2005 at the 5th Annual Golf Outing, the foundation recognized Marty Scaminaci as the first recipient of the "Zach Award." Marty Scaminaci has been a supporter of the

Foundation since its inception. He was introduced to the foundation by supporter and former board member Melanie Villapando. As a father he immediately understood our drive to raise funds for the research. He helps annually by coordinating prizes and beverages for multiple events, attending events and was the Head Judge at our First Open Toe Shoe Party. Marty fits helping the Foundation into his busy schedule along with his duties as husband to Laura and father to Todd (14), Joey (12), Matthew (8) and Alyssa (6) all amidst traveling while serving as Director, Acquisition and Integration at Pepsi Americas in Rolling Meadows. Thank you Marty for all of support and dedication, you are a shining star! We are truly blessed to know you.

ZAK AND LIZZIE:

A Tag-a-long Trio Fall 2006

Keep your eyes peeled for the second installment of *Zak and Lizzie: A Tag-a-long Trio*: the artistic talents of illustrator Corasue Nichols combined with the magical writings of author Ann Malokas have a surefire sequel on its way to readers. *Zak and Lizzie: A Tag-a-Long Trio* introduces Zak's brother Benji and helps us to understand the amazing journey of the sibling of a special needs person. Zak, Benji and Lizzie take us through the highs and lows of being the sibling of a brother who sometime walks with the need of a helping hand, but other days sings like an angel. Don't miss this amazing story; we expect it to be available on our website and in bookstores by Fall 2006.



Continued from cover...

WHAT IS OPTIC NERVE HYPOPLASIA?

(sometimes called septo-optic dysplasia or deMorsier's syndrome)

Optic nerve hypoplasia is the under development or absence of the optic nerve combined with possible brain and endocrine abnormalities. ONH is the SINGLE leading cause of blindness and visual impairment in children. In some instances ONH includes agenesis (absence) or abnormal development of the corpus callosum and septum pellucidum. These abnormalities can be minor and not cause abnormal brain functions or the brain function can be affected ranging from mild to severe. The areas that can be affected involve gross and fine motor skills; intelligence, speech and interacting with people and in some people these abnormalities cause seizures.



Jack Steinburg and Cambree Wilbanks, faces of ONH

The development of the pituitary gland can also be affected by this disorder. The pituitary gland is found at the base of the brain. It is the body's master control gland; it makes and directs important hormones required for growth, energy control and sexual development. When a person doesn't make hormones correctly this is called hypopituitarism. The lack of these hormones can cause a great deal of problems for the children who are missing them.

Children need growth hormone to grow normally, control their metabolism, grow and maintain strong bones. The thyroid hormone contributes to the bodies' ability to grow normally and helps control the bodies' metabolism (ability to make energy). The pituitary gland also signals the adrenal glands to produce cortisol. Cortisol is needed in times of physical and emotional stress. The pituitary gland produces ACTH, which signals the adrenal gland to produce cortisol in time of stress (such as surgery, illness, dehydration). In addition, you can have problems with development of sex hormones, low blood sugar and if the body is producing too much ADH causing the body to produce too much urine.

All of these endocrine conditions can be managed through daily medication routines. The medications are delivered by nose, mouth or injection. Even with close and careful monitoring of these endocrine deficiencies can be dangerous to those afflicted...without careful monitoring these conditions can be deadly. ❤️

(This information was summarized from *Optic Nerve Hypoplasia, A Guide for Parents*, written by Dr. Francine Kaufman, Dr. Neal Kaufman and Dr. Mark Borchert. For a complete guide, please see our website www.onesmallvoicefoundation.org).

Upcoming Events

Thank you in advance for attending our events. Please know we offer a variety of events for your enjoyment. We appreciate your support and do not expect that everyone is interested in attending all events.

We are currently looking for volunteers, if you are interested in volunteering to help with an event or would like to be a part of an event committee, please email us at onesmallvoice@earthlink.net

2ND ANNUAL OPEN TOE SHOE PARTY L.A.

Saturday, April 29, 2006
Viceroy Hotel in Santa Monica
12Noon-3pm

The celebrity judge panel will select the top three contestants. The contest will offer incredible prize packages and promise to be fun. We will also have an amazing silent auction with something for everyone! If you are interested in joining us in Los Angeles, please let us know as we will have a special block of rooms at a special rate. Generously underwritten HSM Electronic Protection Services.

6TH ANNUAL GOLF OUTING

Sunday, June 11, 2006
Maple Meadows Golf Course
272 Addison Road in Wood Dale

\$125.00 per golfer
\$25.00 per additional Barbeque guest

Texas Style Barbecue immediately following event at the Clubhouse! Great Contests and prizes, including a chance to win a Saab convertible from Patrick Dealer Services! Please make checks payable to One Small Voice Foundation, include the names and phone numbers of your foursome and mail to One Small Voice Foundation, P.O. Box 644, Elmhurst, Illinois, 60126. If you are interested in sponsoring a hole or the barbecue or have any questions, please call Debbie at 630/620-6637. On-line registration will be available.

**Assigned tee times will be posted on our website one week prior to event, registration deadline is Friday, May 26, 2006. (www.onesmallvoicefoundation.org)*

***If you do not have a foursome and would like to golf, we would be happy to place you with one.*

4TH ANNUAL 5K FAMILY FUN WALK

Sunday, September 17, 2005
Save the date...more information coming soon!

Please watch our website for more details to come regarding events! ❤️



Winners of the children's race

4 on the 4th

JULY 4, 2005

We would like to extend a special thanks to the Elmhurst Runner's Club for hosting the 1st Annual 4 on the 4th and 1 mile children's run. The club generously donated the proceeds from the Children's Run to the One Small Voice Foundation. Thank you to Susan May and Todd and Karen Ripperda and to everyone from the club and the race volunteers for your support and in choosing the One Small Voice Foundation; your donation helped make 2005 one of our best years ever! Thank you again for your support!



Thanks to our Corporate Sponsors

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- Results One Financial
- Shuz Magazine
- Siri Thai
- Southwest Airlines
- The Spice Merchant and Tea Room, Elmhurst, Illinois
- Stevenson Entertainment group
- Tannin's
- The Tonight Show with Jay Leno
- Vision Mailing Services
- William Whatley and William Whatley International Salon
- Yorktown Shopping Center
- The Young and the Restless
- ZGraphics, LTD

A SPECIAL THANK YOU

to Lombard Cub Scouts Pak 40 and their parents.

They were an amazing part of the success of the 2005 5K Family fun walk. Thank you for all of the pledges you raised and for all of your help cleaning and setting up.

Photo Gallery YOU ALL HELPED MAKE 2005 A GREAT SUCCESS!



Golf Outing – Michelle, Diana and Chris



5K Walk – Casey Szczap giving a massage to a tired walker



5K Walk – Benji with his teachers from Fairwood Kindergarten



Open Toe Shoe Party L.A. – Susan Stuart, Krisha Wilbanks, and other winners



101.9 Radiothon – Max with Zach during the Radiothon



5K Walk – Zach and Kyle



5K Walk – Benji and Ethan, our littlest walkers

Love is Blind was an incredible two part event that took place in 2004-2005. The first part was 11 amazing artists and two dedicated art therapists painting the meaning of love to them. These beautiful works have been transformed into amazing note cards. That are available for purchase. Please call or email Debbie Katzbeck at 630.620.6637 or onesmallvoice@earthlink.net. The cards are



\$10.00 per package plus shipping.



A sampling of the Final Masterpieces.

UNITED WAY

Dear Friends of the Foundation,

If you work for a corporation and are encouraged to donate to United Way, please know these donations can be designated to go to the One Small Voice Foundation. Please file the appropriate paperwork when signing up for United Way and these donations can further help the children afflicted with Hydrocephalus and Optic Nerve Hypoplasia.

If you need any additional information in order to expedite this donation, please call Debbie Katzbeck at 630/620-6637.

Thank you,
One Small Voice Foundation Board of Directors

KOHL'S CARDS

ATTENTION SHOPPERS!

We have joined forces with Kohl's department stores to raise money for the Foundation. If you purchase a Kohl's gift card from the Foundation, 5% of your purchase goes to the Foundation. Please call Cathy Baker at 630/739-5297 if you would like to purchase a gift card or stop by The Spice Merchant and Tea Room at 108 W. Park Blvd, Elmhurst, phone 630/941-7288. They are great to keep around for last minute presents or for your own shopping. Thank you again for your support.

101.9 FM THE MIX AND ONE SMALL VOICE FOUNDATION

We would like to extend a special Thank You to 101.9 FM The Mix radio station. We are proud to have Eric, Kathy, Melissa, Swany, Barry, MaryEllen and the Big Karwowski as friends of the Foundation and Children's Memorial in Chicago. In 2005, we were blessed to be the recipients of The Mix's annual cd box set proceeds as well as receiving their support from PSA's for all of our events, and to have the Road Crew at our 5K walk. The Mix is family to the One Small Voice Foundation and we thank you for all of your support to our foundation and to Children's Memorial Chicago with the radiothon. We love you and you are all amazing! ❤️



Eric and Kathy with the Katzbecks at the annual radiothon.

Design by ZGraphics, LTD. Printing by Genesis. Mailing by Vision Mailing Services. Postage from The Orion Group.

One Small Voice Foundation is a nonprofit 501(c)3 organization supported by the generous contributions of individuals, corporations and foundations. We thank you for your support.

MISSION STATEMENT: Inspired by the love and generosity of our supporters, we strive to give a voice to all children with Optic Nerve Hypoplasia and Hydrocephalus. We will educate and inform others about these disorders. We will support research efforts to benefit children with Optic Nerve Hypoplasia and Hydrocephalus. Our mission will be accomplished with the highest level of integrity and commitment.

email: onesmallvoice@earthlink.net
www.onesmallvoicefoundation.org

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ONE SMALL VOICE FOUNDATION

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